



ALERT

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

BLAMING OTHERS: Prejudice, Race, and Worldwide AIDS

FEBRUARY, 1989

(Book Review by Rev. Steve Pieters)

A highly recommended study of the worldwide "epidemic of blame," occurring around the world because of AIDS, has been published by the Panos Institute, in association with the Norwegian Red Cross. BLAMING OTHERS: Prejudice, Race, and Worldwide AIDS, by Renee Sabatier, is an analysis of the effects of fear and prejudice on the AIDS epidemic, throughout the entire world.

Third World journalists and researchers contributed to this report, which describes the ways in which AIDS has created an "epidemic of blame," which in turn has enflamed racist attitudes and behaviors throughout the world. AIDS is seen as increasingly targeting the most disadvantaged populations and as such, it is a vehicle for the further oppression of groups such as blacks, hispanics, and gays in the United States, and the black majority in South Africa.

The book asks hard questions, like "Why does the average US white man with AIDS live two years after diagnosis, and the average US black man only 19 weeks?" It is recommended (and used) by the US National Minority AIDS Council, the National Urban League, the Mexican Women's National Association, and the National AIDS Education and Prevention Program of the National Council of Negro Women.

For copies of this book, or the latest edition of AIDS and the Third World, send \$9.50 each to The Panos Institute, 1409 King Street, Alexandria, VA 22314.

AIDS AND ITS METAPHORS **(by Susan Sontag)**

(Book Review by Rev. Steve Pieters)

When I was first diagnosed with AIDS, I read Susan Sontag's Illness as Metaphor. Out of her own experience of cancer, and through research, Sontag argued that societies have long attributed meaning to disease that isn't there, which creates the stigmatization of the persons with the disease. She illustrates her point with the 20th century US reaction to tuberculosis and cancer. Illness as Metaphor suggested to me, as a newly diagnosed person with AIDS, that there would be a tendency to find a metaphorical understanding of the syndrome. Some people would see the illness as a punishment, some would see it as some sort of cosmic lesson, and some would try to describe personality types who are prone to the illness, and some would try to make up absolutes, like "your condition is 100% fatal."

Instead, she suggests, we would be wise to see illness as "just a disease." It doesn't mean anything about the person, or the society they live in. Illness just is. My interpretation of her thesis became a powerful tool for me in demystifying AIDS, in coping with the knee-jerk guilt and fear I felt. In her own words, "The purpose of my book was to calm the imagination, not to incite it. Not to confer meaning, which is the traditional purpose of literary endeavor, but to deprive something of meaning." (AIDS and its Metaphors, p.14) In making AIDS "just a disease," I found empowerment.

So imagine the anticipation I felt when I saw AIDS and Its Metaphors in the bookstore. Sontag's argument goes in one direction I anticipated, and effectively critiques the common fundamentalist reaction to AIDS as divine punishment on a decadent society.

But she also shows how AIDS is being used politically throughout the world, how each area of the world seems to blame another (the United States and Western Europe tend to believe the Africa green monkey theory, which Sontag points out feeds racist sentiment; Africans and the Soviet Union blame US biological warfare.) She further critiques the tendency to use military metaphors in illness (the body as battlefield).

My one disappointment with the book was that Sontag never addressed the New Age approach to AIDS, which is fraught with metaphors around AIDS. Many practitioners find meaning even in individual opportunistic infections. She approached the subject, but then writes that "one way in which AIDS, some of whose metaphors overlap those of cancer, seems very different from cancer...is that no one is tempted, not yet at least, to psychologize it." Whenever I have heard persons with AIDS talk about "creating their illness through self-hatred, and curing it through self-love," I have wondered how Susan Sontag would react. Apparently she does not know of the New Age movement among people with AIDS.

Sontag admits that AIDS is currently the disease most fraught with metaphor. But even AIDS can become "just an illness" when it is better understood, and treatable. She suggests that detaching AIDS from its metaphors can be not only liberating but consoling (p.94). By and large, that has been my experience.

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AIDS AND ITS METAPHOR, (Cont'd)

And yet a core quest of the spiritual journey is the search for meaning. Victor Frankl suggests in "Man's (sic) Search for Meaning" that human survival in catastrophic situations is dependent on continuing the search for meaning. Religion, even spirituality, is highly dependent on metaphor. I have spent a lot of energy looking for meaning in my own experience of AIDS. Can we allow AIDS to be metaphor-free, while at the same time we attempt to redeem the catastrophe through finding meaning? Is Sontag's thesis antithetical to spiritual life?

This short, readable book will provoke many such questions and discussions.

PWAs IN THE WORKPLACE - PRACTICING WHAT WE PREACH

*(Reprinted with permission from:
Network News: Conference Chronicle,
Vol. 2, No. 16, December, 1988)*

"We've been out there preaching about AIDS and the workplace," said Don Schmidt, former executive director of New Mexico AIDS Services. "It's time we point to our own work forces and role model." Addressing NAN Skill Building Conference participants in a luncheon panel on workplace issues, Schmidt pointed out that even AIDS service organizations must deal with their own "us verses them" attitude toward people with AIDS (PWAs) in the workplace.

Schmidt, who was diagnosed with pneumocystis pneumonia a year ago, said employers - particularly those in what he called the "AIDS industry" - should provide "reasonable accomodation" to PWAs, such as allowing them to take naps, "job-share" with another staff person, do part-time work or work at home. But he noted that this flexibility is hard to come by in AIDS organizations "when 60 to 80 hour work weeks are the norm."

Phill Wilson, who conducts workplace trainings and is a PWARC, said, "A joke was played on us: people are living with AIDS and we're not prepared to deal with that." Wilson said AIDS organizations "have not moved beyond the crisis mode." AIDS, he said, is "going to be with us for some time," and AIDS organizations therefore must adapt to that reality by altering expectations to somewhere within the realm of what is reasonable.

"The bottom line," Wilson said, is for AIDS organizations "to create a workplace that's good for people, that accounts for personal realities." Wilson said AIDS service organizations "need to change from being 'first generation' organizations (run by their founders) to 'second generation' organizations which recognize that there are limits to job responsibilities."

Including PWAs and PWARCs in the workplace is a challenging proposition, certainly. But "it's time to discuss this issue openly - not behind closed doors of the executive director or personnel director," said Lew Katoff, director of client services with New York City's Gay Men's Health Crisis, Inc. and a PWA.

Reaching a mutually workable, "reasonable accomodation" has its rewards, according to the panelists. Katoff, for example, said PWAs "force each of you to be a care partner" by bringing an increased sensitivity to the needs of clients. Schmidt pointed out how essential this sensitivity is because for many in the AIDS industry, "there's a real problem with folks not knowing who they're serving." He added that having people with AIDS or ARC on staff "can provide a face for the epidemic" - a face that folks both inside and outside the organization need to see.

FIFTH INTERNATIONAL CONFERENCE ON AIDS

Toward a human and community-based approach to AIDS: By choosing the theme "AIDS, the scientific and social challenge", the organizers of the 5th International Conference on AIDS, taking place in Montreal, CANADA, June 4-9, 1989, have clearly indicated that they do not consider AIDS exclusively a health problem to be solved by scientists but also a social problem which concerns the population as a whole, and more particularly certain social groups.

The objective is to structure this international conference around two axis, one biological and medical, the other social, multidisciplinary and community-oriented. A real social and community approach to AIDS implies intervention and information programs based on social and cultural characteristics and the involvement of various groups in preventive and supportive approaches.

Communications on the social approach to AIDS will be organized around the 16 major themes. At this stage, there are a limited number of themes relevant to the 5th International Conference on AIDS: * Community involvement models; * prostitutes and their clients; * anxiety in sero-positive individuals; * prevention strategies for various groups in different social and cultural contexts; * illiteracy and information methods; * cultural concepts of sexuality; * AIDS and the community; * exhaustion of treatment staff; * AIDS and women; * AIDS and the gay community; * AIDS and poverty; * the lessons to be drawn from the history of major epidemics; * intervention among infected individuals, their families and their networks; and * appropriate needle use.

Anyone wishing more information regarding this conference should write to: Fifth International Conference on AIDS, 1010 St. Catherine West, Suite 628, Montreal, Quebec H3B 1G7 or call (514) 874-4006.

BLACK WOMEN "FALLING THROUGH THE CRACKS"

*(Reprinted with permission from:
NETWORK NEWS, Vol. 2, No. 16, Dec 1988)*

More than 90 women met in Washington, Oct. 17-18, for a Conference titled "From Cries and Whispers...To Action: Black Women and AIDS." The Conference, sponsored by the Atlanta-based National Black Women's Health Project (NBWHP), was planned in order to develop "a national network of black women working collaboratively to influence the development of policy and programs in support of black women affected by the epidemic and [to] encourage the development of appropriate community-based prevention and support programs," according to pre-conference material.

According to S. Denise Rouse, conference co-chairperson, "The primary issue that came out of the conference was that Black women are falling through the cracks. Black women with AIDS are the most disenfranchised group of people in the country. They were the people who were falling through the cracks before AIDS, whose lives were very precarious, so what's happening now is just a continuance of the same situation."

Rouse explained that conferees discussed extensively and made recommendations for systemic changes, working to create change in the lives of the women who were going to be most vulnerable to the epidemic, and change in the institutions that provide services to these women.

The meeting was permeated by a feeling that women doing AIDS work aren't getting the kind of support they need, Rouse said. For this reason, she added that one of the conference's main recommendations was that women who are involved in providing AIDS-related services should join or create support groups for themselves.

Venus Medina, the National AIDS Network's resource contact for women's issues, spoke of the "desperate" need for conferences, focus groups and other supportive settings for women in AIDS work. Said Medina, "The two days of coming together, sharing and supporting each other needs to happen in more regions and more often."

Discussion also centered on ways in which black women are at risk for HIV transmission and what can be done to prevent it. "For black women," said Rouse, "it's largely a substance abuse-related transmission process. Either they're doing the drugs themselves or they're associated with someone who's doing the drugs. As a part of trying to figure out what needs to be done, we saw the need for the generation of massive support for substance abuse treatment, to help community groups get drugs out of their neighborhoods, and for alternatives for employment so that people don't have to be tied to the drug industry as their source of income."

NBWHP was established in 1981 to address through national and local media productions, educational presentations, self-help chapters, networking, a national newsletter, and national and regional conferences, the health issues facing black women and their families. NBWHP can be reached at 404/524-7237.

ACYCLOVIR PROVES INEFFECTIVE IN SOME PEOPLE WITH CHRONIC FATIGUE SYNDROME

The antiviral drug acyclovir has proved ineffective in treating the symptoms of chronic fatigue syndrome (CFS) in a select group of patients, according to a report in this week's New England Journal of Medicine. CFS, formerly called chronic Epstein-Barr virus (EBV) infection, is a poorly understood illness marked by long-term, debilitating fatigue accompanied by recurrent flu-like symptoms such as fever, sore throat, aching muscles, and inability to concentrate.

According to Dr. Stephen E. Straus, chief of the Medical Virology Section of the National Institute of Allergy and Infectious Diseases (NIAID) and senior author of the report, "Our findings suggest that active EBV infection is not a primary cause of CFS symptoms. However, EBV as well as other viruses may still act to trigger the illness."

CFS can affect anyone, but those seeking medical help have mainly been white women in their 20s or 30s. While the syndrome has been widely reported in the United States, Canada, Europe, and Australia, the actual number of people with CFS is unknown. No known proven treatment or cure for CFS now exists, and doctors currently treat patients symptomatically.

Twenty-seven patients, 19 women and 8 men, enrolled in the double-blind, placebo-controlled study. All had had debilitating fatigue and other classic CFS symptoms for an average of 6.8 years. In addition, all had a particular profile of antibodies against EBV, suggesting a possible acute or reactivated EBV infection. The researchers thought that this particular subset of CFS patients might respond best to acyclovir treatment. Acyclovir inhibits EBV replication in the laboratory and in animals, and has also anecdotally been reported to help some people with CFS.

Of the 24 patients who completed the trial, 21 reported feeling better during treatment. But nearly equal numbers of those on acyclovir and placebo (11 and 10, respectively) reported that their symptoms improved. Seventeen patients reported temporary improvement of symptoms, lasting no longer than a few weeks after treatment was stopped; four patients noted marked improvement for at least one year. Surprisingly, three of the latter patients began feeling better during placebo treatment. Moreover, those who said they improved on acyclovir could not be distinguished on the basis of laboratory tests from those who reported no improvement.

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ACYCLOVIR PROVES... (Cont'd)

The study authors say they believe "the clinical improvement observed in most patients reflected either spontaneous remission of the syndrome or a placebo effect."

The study consisted of five phases, including two 37-day treatment phases. Patients were randomly assigned to receive either acyclovir or placebo for the first treatment. A 6-week hiatus followed, after which they received the alternate therapy.

An aggressive intravenous treatment regimen consisting of high-dose acyclovir or placebo was administered to patients in the hospital every eight hours for seven days. Patients then returned home and took 800-mg acyclovir or placebo tablets four times daily for 30 days.

Patients assessed their own response to treatment by filling out daily self-assessment forms and psychological tests. Each day they also noted their body temperatures and levels of activity, energy, and sense of wellness. Once each week during the 28-week study they completed a mood questionnaire measuring anxiety, depression, anger, vigor, fatigue and confusion.

According to Dr. Straus, "Improvement in fatigue correlated significantly with mood. Patients who felt better also showed lower levels of anxiety, anger, and depression. We could not determine whether their mood improved because they felt better or whether they felt better because their mood improved."

NIAID FUNDS MAJOR STUDY OF HIV INFECTION AMONG HETEROSEXUALS

Heterosexual men and women who are not intravenous (IV) drug users but who are at high risk for HIV infection will be the focus of a major new epidemiology study announced today by the National Institute of Allergy and Infectious Diseases (NIAID). NIAID has awarded three contracts for a collaborative, prospective study of the transmission and natural history of human immunodeficiency virus (HIV) infection among some 2,000 heterosexuals. Study centers in Newark, New Jersey, and Brooklyn, New York, and a data coordinating center in Ann Arbor, Michigan, received the contract awards. First-year funding for the 5-year contracts totals nearly \$4 million.

Dr. Anthony S. Fauci, director of NIAID, emphasized the importance of this study for designing more effective strategies to prevent and treat HIV infection. Although only 4 percent of all adults diagnosed with AIDS since reporting began acquired the disease through heterosexual contact, this mode of transmission accounts for 30 percent of all AIDS cases in women. Heterosexual HIV transmission usually occurs by sexual contact with an IV drug user.

The study sites were chosen in part because they are located in inner-city areas populated by large numbers of HIV-infected drug users, a potential reservoir of infectivity for heterosexuals.

The overall goals of the study are to determine:

- * The natural history of HIV infection in non-homosexual women and men who have no history of intravenous drug use;
- * sexual and other behaviors associated with the transmission of HIV in such a population;
- * biological and environmental cofactors associated with the acquisition of severity of the expression of HIV infection in such a population.

Among the factors to be evaluated for their influence on the transmission and course of HIV infection are the presence of other sexually transmitted diseases, co-infection with HTLV-1 or other retroviruses, infectivity of the source case, and use or non-use of condoms. In addition, the investigators will study the natural history of HIV infection by following patients clinically while simultaneously assessing their immune system functioning.

Neurologic, neuropsychologic, and neuroradiologic testing of some seropositive study participants will be carried out to determine how HIV infects the brain and the nervous system. Also, the progress of HIV infection in heterosexuals will be compared with similar data accrued from people who have acquired HIV infection through other routes, for example, intravenous drug users. In addition, the study will assess educational intervention strategies.

Those considered at high risk for HIV infection and therefore eligible to be enrolled in the study include 1) heterosexuals with a history of multiple sexual partners (defined as an average of 10 or more sexual partners per year); 2) those with a history of sexually transmitted disease(s) within the past 5 years; 3) those with known sexual contact with person(s) considered to be at high risk (or engaging in high risk behavior) for HIV infection; 4) those concomitantly infected with or exposed to other fungal, viral, retroviral, bacterial, or parasitic infections, cofactors that might increase the risk of acquiring or the severity of HIV infection.

The New Jersey study will recruit a cohort of 1,000 heterosexual men and women through AIDS counseling and testing sites set up by the state in three health facilities in northern New Jersey. In addition, infectious disease specialists at these facilities and at the UMDNJ University Hospital in Newark will refer patients to the study team.

Unlike the New Jersey study, the New York study will principally focus on recruiting heterosexual women. However, a select group of men who are sexual partners of HIV-positive and HIV-negative female participants will be asked to enroll. Also, steady male sexual partners of women who are initially HIV seronegative and then seroconvert will also be assessed. Strict patient confidentiality will be observed.